

6-1-2003

# Long-Term Care: Informed by Research

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## Recommended Citation

Caro, Francis G., "Long-Term Care: Informed by Research" (2003). *Gerontology Institute Publications*. Paper 6.  
[http://scholarworks.umb.edu/gerontologyinstitute\\_pubs/6](http://scholarworks.umb.edu/gerontologyinstitute_pubs/6)

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long-term care

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Informed by  
Research



This publication by Francis Caro is one of a series of three briefs that identify how research has improved long-term care service delivery and policy in the past and how it might continue to do so in the future. Each brief is based on key themes that emerged from a 2002 conference on building the field of long-term care, which was sponsored by AARP, the Agency for Healthcare Research and Quality (AHRQ), the Retirement Research Foundation, and The Robert Wood Johnson Foundation.

Francis Caro is professor of gerontology and director of the Gerontology Institute at the University of Massachusetts at Boston. He is also editor of the *Journal of Aging and Social Policy* and chairs the Long-Term Care Research Initiative. He holds a Ph.D. in sociology from the University of Minnesota.

**H**ealth services research has contributed to health policy and service developments that have led to major improvements in the quality of long-term care in the United States. This policy brief highlights a few areas in which publicly and privately funded research has informed the long-term care field.

### Activities of Daily Living

In the 1960s, Sidney Katz conducted a series of studies that assessed how well seniors' ability to perform basic tasks such as bathing, dressing, walking, eating, and toileting correlated with their need to receive long-term care. This research led Katz to develop the Activities of Daily Living (ADL) measure,<sup>1</sup> which is now a widely used geriatric assessment tool. The ADL approach is significant because it emphasizes ability to function—which is a more sensitive indicator of long-term care need than underlying diagnoses. The ADL measure is also easy to understand and use.

The ADL measure provides a starting point for service planning in both nursing home care and home health services. It has also proven to be highly valuable for surveys that assess the extent of need for long-term care services in the population and for projections of potential demand for new services. These surveys, in turn, have helped insurance companies to recognize that long-term care could be insured. The surveys provided a basis for carriers to estimate the volume of claims—a key factor in setting rates. The ADL measure also gave insurance

companies an objective basis for determining policyholders' eligibility for long-term care benefits.

Lawton and Brody<sup>2</sup> subsequently developed the Instrumental Activities of Daily Living (IADL) scale, a measure of seniors' capacity for self-care. It assesses how well people can perform tasks necessary for independent living, including using the telephone, grocery shopping, preparing meals, and taking medications. The IADL measure has proven to be particularly useful in planning services for those seeking community-based care.

### Resident Assessment Instrument

The Nursing Home Reform Act of 1987 mandated development of a standardized Resident Assessment Instrument (RAI) for use in all nursing homes as a basis for care planning and service monitoring. A team of researchers and clinicians developed the RAI by synthesizing a substantial body of research on care of residents of nursing homes.<sup>3</sup> In addition to the activities of daily living discussed earlier, the RAI measures psychosocial well-being, cognitive status, vision patterns, communication patterns, bowel and bladder continence, chronic diseases, activity patterns, skin problems, pain symptoms, and oral and foot problems. Use of the RAI in care planning has been shown to improve care practices and health outcomes for nursing home residents.<sup>4,5</sup> RAI data are being used as a basis for Medicaid reimbursement for nursing home care in many states and as a

measure of the quality of nursing home care. The instrument has been adapted for international use and for use in home health care. In fact, the Centers for Medicare and Medicaid Services requires that individuals participating in the Medicare Certified Home Health program be assessed by the home health care version of the RAI, called the Outcomes and Assessment Information Set (OASIS).

### Channeling Demonstration

Between 1981 and 1985, the federal government carried out the National Long-Term Care Demonstration, which had a major effect on the development of publicly funded, community-based care in the United States.<sup>6</sup> This project was also known as the Channeling demonstration because it sought to “channel” the long-term care population into the appropriate service settings. The demonstration was

the culmination of an effort to determine whether states could offer publicly funded, case-managed, community-based care without increasing their overall spending. The demonstration attracted a great deal of interest because of elderly people’s preference to live independently and the states’ need to limit spending.

The Channeling demonstration was conducted after a series of state demonstrations had produced mixed results. The state findings were also surrounded by uncertainties because of imperfect research designs. The Channeling study was conducted on a large scale using formal experimental methodology in an effort to prevent design flaws from influencing the results.

The demonstration included 10 states. It found that, while community-care models were often welcome by recipients and their caregivers, they led to overall increases in public spending for long-term care. While the results were disappointing for advocates of publicly funded community care, the research led public officials to take a more cautious approach in authorizing and administering community-based long-term care programs. The findings also led some public programs to target community care to those most at-



risk of nursing home placement. Moreover, the client assessment and care planning protocols developed for the Channeling program have become a model for community-based long-term care programs throughout the country.

## Caregiving Research

The fact that most long-term care is provided by family caregivers has been thoroughly documented in survey research.<sup>7,8</sup> In 1982 and 1984, the National Long-Term Care Survey included components that focused on such caregivers. The National Alliance for Caregiving and AARP co-sponsored a national survey of caregivers in 1997. That study was a replication of an investigation conducted in 1988 by AARP and The Travelers Foundation.

Researchers have focused particular attention on learning the effects of sustained caregiving on unpaid family members. There is a substantial body of evidence indicating that intensive, continued informal caregiving can adversely affect the physical and mental health of caregivers. Studies have also shown that publicly funded home and community-based services tend to complement informal care. This body of research stimulated the development of various support services and respite programs for caregivers, some of which are state-funded. It also helped justify adding support services for family caregivers to Title III of the Older Americans Act in 2000, and provided backing for proposals to give tax credits to these individuals.

## Ongoing Research

Research continues on some of the long-standing issues in the field. Efficient targeting of publicly funded long-term care services, for example, remains an important concern. In political discourse, public spending for community-based care continues to be advanced as a means of saving money by reducing demand for more costly nursing home care. At the same time, many states are engaged in efforts to raise the clinical barriers for access to Medicaid-financed nursing home care. For these reasons, the questions of clinical eligibility for services and planning cost-effective care remain of vital importance.

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Improving measurements of quality care remains a priority. Some of that research seeks to establish expected rates of decline in functional capacity based on chronic health conditions that can be used as benchmarks in evaluating efforts to improve care.<sup>9</sup>

Researchers are attempting to develop sound, practical measures of quality of life for long-term care recipients that can be used routinely in service evaluations.<sup>10</sup> Some studies are focusing on development of consumer satisfaction measures that can be used for quality assurance in specific long-term care service modalities.<sup>11</sup>



Research remains an important aspect of major demonstration programs. The Cash and Counseling Demonstration, for example, which is supported by the federal government and The Robert Wood Johnson Foundation, is testing whether long-term care recipients can self-direct some of their care. The demonstration gives them substantial discretion to use public funds to purchase services tailored to their own needs, whether that entails hiring help, obtaining equipment, or remodeling their homes. The evaluation research will assess the extent to which clients prefer to direct their own care, the implications of self-direction on quality of care, the effects on caregivers, and the impact on public spending. For more information, visit [www.mathematica-mpr.com/3rdLevel/cashcounseling.htm](http://www.mathematica-mpr.com/3rdLevel/cashcounseling.htm).

### Continuing Need for Research

The long-term care field continues to face major issues that call for research attention. Moving forward, researchers will need to assess how to:

- ▶ Strengthen the long-term care workforce;
- ▶ Draw upon advances in technology to complement human assistance in the provision of care;
- ▶ Improve the division of labor between formal services and informal caregivers in community-based care;
- ▶ Strengthen the relationship between long-term care and management of chronic health conditions;
- ▶ Improve strategies for disability prevention and rehabilitation to prevent or minimize the need for long-term care; and
- ▶ Develop improved approaches to public and private financing.

A sustained investment in research is needed in all of these areas to better understand the underlying issues, to identify promising innovations, and to determine what works and what does not. ▶

### Endnotes

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- 4 Hawes, C. et al., "OBRA-87 Nursing Home Regulations and Implementation of the Resident Assessment Instrument: Effects on Process Quality," *Journal of the American Geriatrics Society*, 1997, Vol. 45, No. 8, pp. 977–85.

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## Related Resources

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Center for Medicare and Medicaid Services (2003), <http://cms.hhs.gov/medicaid/mds20/rai1202ch1.pdf>.

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June 2003